



Standards of Care for Families Experiencing Perinatal Bereavement

Acknowledge Every Loss as Significant

Pregnancy and infant loss are unique and devastating experiences for families. Unlike other types of loss, it is not typically recognized or acknowledged in society. As healthcare providers, it is important to let families know that their pain and grief is valid, regardless of gestational age. Ensure that you are not only acknowledging their loss but recognize that their baby is a person whom they loved very much.

Traditionally, early losses are often seen as less significant than later losses. However, even the earliest of pregnancy losses can be profoundly difficult. That is because parental attachment often begins early in pregnancy. Furthermore, you do not necessarily know the entire story of the couple's pregnancy history. Perhaps they have had several prior losses. Or maybe, they have been trying to conceive for many years. There is no right way to grieve pregnancy or infant loss, so allow the family to grieve in their own way.

Provide Sensitive and Compassionate Care

When offering support to a family who has experienced stillbirth, it is important to remember that this is their experience, not yours. Even if you have experienced a similar loss, remember that this is not about you and that each loss is unique. It is ok to say, "I'm so sorry. I had a similar loss, and I am here to guide you through this." Regardless of whether you have experienced perinatal loss, do not share your opinions or advice unless asked to do so. Be careful not to impose your values or beliefs upon the family. Everyone grieves differently!

It is ok to cry with your patients; however, if you feel yourself losing control, quietly excuse yourself from the room until you are ready to return. For whatever reason, if you are not capable of providing compassionate care, please speak up to your charge nurse or supervisor. Every woman, especially those experiencing such a tragic loss, deserve appropriate and respectful care! Refer to our [11 Tips for Compassionate Care](#) for a detailed description of the following:

- Acknowledge the loss
- Use the baby's name
- Validate the familial roles
- Validate emotions
- Be present
- Be empathetic
- Be respectful
- Be culturally competent
- Be patient
- Provide privacy
- Take care of yourself

Attend to Physical Needs

Women experiencing stillbirth may need extra care and pampering. It is important to make sure her basic needs, such as food, water, and comfort are taken care of. Consider asking dietary to offer a comfort cart with various snacks and beverages for the patient and family. Make it easy to stay hydrated by frequently refreshing her water pitcher.

Women who are experiencing perinatal loss may experience physical pain more intensely, so ensure that you are attending to her pain needs. Following delivery, encourage the parents to shower and rest when needed. Make sure she has tissues handy as there will be lots of tears. Additionally, offer her a washcloth or face wipes to clean her face. Don't forget about the spouse or partner. Make sure to attend to his or her needs as well. Give the family privacy, but check-in on them frequently.

Include the Entire Family

The loss of a child is a deeply emotional and traumatic experience for BOTH parents. Partners are often overlooked, because so much of the attention is focused on the mother. The partner may feel the need to be strong and stoic for his or her partner. Provide the same sympathetic, compassionate care to the partners and include them in the decision-making as much as possible. Their needs are important too.

Siblings can grieve deeply after a stillbirth. While you may have your own strong feelings about how involved siblings should be, it is ultimately up to the parents to decide. Experts recommend giving children the option of meeting and/or holding the baby, as they are best able to determine if they are ready for that or not. However, it is important to remember that forcing a child to do something they are not ready for may cause more harm than good.

Grandparents often grieve twice. They not only grieve the loss of their grandchild, but they grieve for the heartbreak that their own child is experiencing. Make sure to include them in the process. Encourage grandparents to touch, hold, and interact with the baby.

Ensure that the patient has the option to have extended family members, friends, or support persons present. For some families, the presence of family and friends provides comfort to the parents. It can reduce the sense of isolation by having others affirm that the baby is loved and mourned by many.

Diagnosis

Discovering that there is no fetal heartbeat while you are providing care for a pregnant patient can be an extremely distressing challenging situation. It is crucial to respond quickly and compassionately. Here are some steps that you can take:

Be Honest	Let the family know that you are having difficulty finding the baby's heart rate.
Explain Next Steps	Explain what is going to happen next. Are you going to have the physician perform an ultrasound?
Provide a Timeline	Tell the patient when you will be back and stick to it. Even if it's just to let give an update.
Communicate Gently	Deliver the news in a clear but gentle way. "I'm so sorry. I am unable to detect a heartbeat. Your baby has passed away." Be prepared to answer questions.
Provide Privacy	Ensure that the patient and their families have a quiet space to process the news. It is a good idea to provide the family with a pen and notepad to write down questions they may have.
Explain What to Expect	Share information on what comes next regarding medical care, tests or procedures, or follow-up appointments. Preparing for a stillbirth can help lessen the trauma. Let families know about how long it will take and what will happen during postpartum.

Provide Verbal and Written Information

Families going through miscarriage, stillbirth, or neonatal death may be overwhelmed with emotions and may not absorb all the information presented to them verbally. Providing both written and verbal information:

- **Improves understanding.** Providing written information alongside verbal communication ensures that they have a comprehensive understanding.
- **Promotes Informed Decision-Making.** Families facing perinatal loss often need to make difficult decisions regarding testing options, funeral arrangements, and other aspects of care. Providing written information ensures they are well-informed and have additional resources to help them make their decisions.
- **Accommodates Different Learning Styles.** People have different learning styles. Some individuals may prefer to read, while others prefer verbal communication. By offering both, you can cater to the diverse preferences of families.
- **Provides Repetition.** Because grief can impact a person's ability to concentrate and focus, it is important to provide repetition for increased understanding.

Create a Safe and Supportive Environment

Ensure that the physical environment is peaceful, private, and comfortable for the parents and family. Perform a sweep of the environment and remove anything that could cause discomfort. Avoid high traffic areas and rooms near the nursery.

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- Ensure that the room is a comfortable temperature. Dimmed lights or natural lighting can help create a calming space.
- Ensure that there are tissues at the bedside.
- Determine how you will let ancillary staff know that the patient is experiencing a loss.

Provide Continuity of Care

It is important to provide continuity of care whenever possible. This allows the family to develop a trusting and supportive relationship with their nurse or other healthcare provider. Trust and familiarity can facilitate open communication and a sense of safety and comfort in expressing emotions. The nurse assigned to care for a family experiencing perinatal loss should, ideally, not have any other assignments.

Offer Referrals

Families experiencing perinatal loss often require more support than the nurse or physician can provide. Does the family desire a special ceremony such as a baptism or blessing? Ask the family if they would like the hospital chaplain to perform these or other rituals, or just to offer spiritual support. You can also offer to call their own personal clergy. Consider a referral to the hospital social worker. He or she can help connect the family to resources in their area.

Assist to Develop a Birth Plan

Anticipating a stillbirth can be a scary and emotionally draining process. A birth plan, such as our Wishes for Delivery, can help those grieving to feel more in control of the process and outline all the options available. This can help those grieving to make more informed decisions and feel more empowered during a time of immense sadness. Let the family know that there are no right or wrong decisions. It is important to be non-judgmental and respect the choices made by the family.

- Clarity- A birth plan is a tool that allows families to communicate their preferences and decision to the healthcare team in a clear manner.
- Empowerment - Many parents feel a lack of control when experiencing the loss of a child during pregnancy. Completing a birth plan empowers families to make decisions regarding their birth, baby, and other delivery related options.
- Facilitates Discussion - A birth plan is a valuable tool for enhancing informed-decision making. A birth plan can facilitate discussion, promote questions, and provide a listing of options.

Take Photographs

Photographs are valuable mementos for parents who have experienced the loss of a baby through pregnancy loss or the death of an infant. They provide validation of the baby's existence and will likely be a source of comfort for the parents. This is the **ONLY TIME** that you can capture these memories, so take many photos. Take photos of the baby by himself or herself as well as the family interacting with the baby. Also consider enlisting the help of professional volunteer photographers through the non-profit organization, Now I Lay Me Down to Sleep.

Occasionally, you will have a family that does not want photographs. Let them know that nearly all parents who have chosen not to have photos taken regret their decision. Offer to take and store their photos in case they ever change their minds. Alternatively, you can place the photos in a clearly labeled, sealed envelope, for the family to take home with them for when they are ready to view them.

Normalize Interactions with the Baby

Following the delivery, it is important to attempt to normalize the situation. Depending on the gestational age of the baby and how long it has been deceased, the condition will vary. Try to describe the condition of the baby in an effort to prepare the family so they are not surprised by the baby's appearance. Assure the family that you are here to guide them through the process.

No matter how much you prepare a family, they may still be initially shocked by their baby's appearance. Tell them their baby is beautiful. You can help them recognize his or her beauty themselves by pointing out the ways in which she looks like mom or dad. Even very small babies usually have some feature that can be connected to mom or dad. For example, if the baby has very long toes, ask where the baby inherited that feature. In addition to normalizing the situation, it helps mom and dad to bond and connect with their baby.

Encourage the family to hold, rock and read to baby, as many parents who did not later regretted their decision. Parents will often model your behavior. If they see you holding and talking to the baby, they may feel more comfortable interacting with the baby as well.

If the parents have not already done so, encourage them to give their baby a name and use it with all interactions. Treat and acknowledge the baby as a person who is real and loved. Assist the family to bathe, diaper, and dress the baby. These actions not only create memories, but they also help families feel more connected.

Create Keepsakes

Stillbirth keepsakes are meaningful and treasured mementos that provide comfort and a connection to a lost baby. They serve as tangible reminders that the baby existed. There are many organizations that offer free keepsake items to healthcare facilities. Refer to the [Meaningful Memories](#) page for a list of ideas.

Explain Burial Options

Burial options following perinatal loss are an important consideration for the family, and they should be provided with all the choices that align with their preferences and cultural or religious beliefs. Remember that each family's experience with perinatal loss is unique, and the choices they make are deeply personal. The healthcare provider's role is to offer guidance, support, and information while respecting the families wishes. Here are some common options:

- **Traditional Burial** - A traditional burial involves interring the baby's remains in a designated cemetery plot.
- **Cremation** - Cremation involves the process of reducing the baby's remains to ashes. The ashes are then placed in an urn or another container of the family's choice.
- **Hospital Burial** - Some hospital facilities provide cremation at no cost; however, it is important that you are aware of your facilities process. At many facilities, the baby is cremated with other surgical specimens. The ashes will not be returned to the family and there will be no gravesites or markers.
- **Memorial Gardens** - Be aware of any non-profit organizations in your area that may offer free or discounted burials for perinatal loss.

Provide Unlimited Time with Baby

Understand that time with baby after pregnancy loss or infant death is important as this is the only time families have to bond and create memories. Encourage the family to spend as much time as desired with their baby. They should not feel rushed!

If your hospital has a CuddleCot or Caring Cradle, offer it to the family to allow for more time with the baby. Alternatively, you can also use ice packs to help keep the baby cool but remember to refresh them often.

Respect the family's wishes and let them decide when they are ready for the baby to leave the room. When the family is ready for you to take the baby, be respectful. You can carry the baby, place him or her in a bassinet, or utilize a Moses basket if you have one.

DO NOT place the baby in a plastic bag, specimen container or cardboard box. Remember, this is their child that they love!

Discharge

Leaving the hospital after stillbirth is an incredibly painful experience for parents. Parents are often left with empty arms and a broken heart. Ensure that the patient has privacy when leaving and will not encounter other mothers and their babies. Again, make sure you have given them printed copies of all the information that was discussed.

It is important customize the instructions to meet the specific needs of the patient. Make sure that the materials that you provide are appropriate and do not include information that can cause distress, such as "how to feed your baby", for example. Here are some common components to include:

- **Physical Recovery** - Explain that physical healing occurs before emotional healing. Discuss any specific physical care instructions, such as perineal or incisional care. Let the patient know when they can resume normal activity. Advise the patient to avoid intercourse until after her physician says it is ok to do so, usually about 6 weeks.
- **Emotional Support** - Although parents may not desire counseling or support groups at this time, provide written information on local and virtual options if they change their minds. Provide contact information for mental health providers that specialize in perinatal loss. Refer to our [Additional Resources](#) page for a list of support options in the state of Missouri. For other areas, search providers that specialize in perinatal loss at Postpartum Support International at www.psidirectory.com.
- **Lactation after Loss** - Depending upon the length of the pregnancy, a woman may begin to lactate. It is important to let families know their options as some women find comfort in donating their breastmilk to other babies in need. If your patient is interested in banking their breastmilk, The Human Milk Banking Association of America is a great place to start. If your patient does not want to donate breastmilk, provide her with information on suppressing lactation. While there is no “magic” way to stop lactation from occurring, there are things the patient can do to hasten the process and lessen her discomfort. Refer to our [Lactation after Loss](#) patient brochure for additional information.
- **Stages of Grief** - Provide the patient with information on the stages of grief. However, it is important that the family knows that their grief will likely come in waves and there is no timeline.
- **Self-care Information** - Give the patient and family permission to take care of their physical and emotional needs.
- **Warning Signs** - Educate the patient about potential complications and when to seek immediate attention.

Postpartum Follow-Up

There is little worse for a man or a woman than to believe that their child has been forgotten. It is important to let them know that you remember them and their baby. One way that you can do this is to mail a sympathy card, signed by the healthcare team, to the family. Write a personal note letting them know what you remember about their baby.

You can also honor the baby by mailing a card on the baby’s first birthday. Create a perinatal loss log, organized by month, and then mail the cards at the beginning of each month. Determine who will be responsible for maintaining the log and mailing birthday cards. Also consider hosting a memorial event and inviting the families to attend.

Consider hosting an annual memorial service and invite your patients and families to participate. Refer to [Hosting Remembrance Events](#) page for additional ideas.

Identify the Stakeholders

Identify the stakeholders within your organization that have a role in perinatal loss. As you can see from the list below, perinatal loss has the ability to touch nearly every department within a hospital. These individuals and teams that you identify are the people that need education and support.

- Nurses
- Obstetricians
- Surgical technicians
- Lactation consultants
- Dietary
- Hospital Chaplains
- Social Work
- Housekeeping
- Emergency Department
- Surgical Services
- Radiology
- Laboratory

Provide Ongoing Education for Healthcare Providers

Providing ongoing education is crucial to ensure that healthcare professionals have the necessary knowledge and skills to provide care and support for grieving families. Consider providing access to a library of relevant books, articles, research papers, and online resources to for nurses to utilize as an in-the-moment resource.

To figure out where to start, conduct a learning needs assessment. Are there certain topics that are more challenging? You can accomplish this by conducting surveys, interviews, or focus groups. Continue to provide ongoing training throughout the year, ensuring the nurse have opportunities to refresh their knowledge and skills regularly. Offer a variety of training formats including in-person workshops, online learning, or webinars. Incorporate real-life case studies and scenarios into training sessions to make them practical and applicable.

Support for Healthcare Providers

Determine how your organization will provide emotional support for team members caring for families experiencing perinatal or infant loss. Establish peer support groups and consider offering a debrief following pregnancy loss or neonatal death, especially if it was unexpected. Provide a safe space for team members to share their experiences, emotions, and challenges with perinatal loss.

Assign experienced mentors to guide and support healthcare professionals, especially if they are newer to providing perinatal bereavement care. The mentor should routinely check-in with the mentee to provide support and resources both during and after caring for a family experiencing loss. He or she should encourage the healthcare provider to perform self-care activities, such as taking breaks and eating meals.



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